

Johnson, Sally

Subject: FW: Hearing to be held on Autism Insurance Bill

Our Story:



In December of 2006, my son Chase was diagnosed with PDD-NOS, Pervasive Development Disorder- Not Otherwise Specified. To anybody that hasn't been initiated into the ASD world, it's what some call "high-functioning Autism", "Autism Light", "Atypical Autism", or "just a nice way to say your son's autistic without using the 'A' word."

Chase is a little over two and half years old. He was developing normally until he was about a year old. We didn't really notice that anything was different about him until about spring of 2006. We just thought that he was difficult and had "early-onset terrible twos". Starting at about 10 months, he was saying some words, then slowly, he started losing his words.

He lost "Momma" and "Dadda" very early. After he was one, he stopped saying words and just spoke in what we thought sounded like Chinese, but the professionals call "jargon". We were amazed at the long attention span he had to be able to watch his Thomas the Tank Engine videos, and how he had so much fun at daycare, he seemed to not even notice when I dropped him off and left. It's amazing and painful to me now to think that's what I saw and didn't realize these weren't actually good things.

At Chase's 2 year appointment, I questioned our pediatrician about his speech. I told her that someone had mentioned "Autism" as a possible cause. As Chase was hugging her, she said, "I can't imagine that there's any possibility that he's Autistic, he's much too loving. An Autistic child wouldn't be hugging me. He does need some help with speech. Call Early On (0-3 years early childhood program through intermediate school districts) and they'll get you some speech help." There it was. The doctor said that he's not Autistic, he's just slow to talk.

Six months later, the doctors at U of M would give me quite a different answer. By then, we saw many of the things about Chase's behavior in a new way. We could see some of the "Autistic tendencies" that we'd researched. So, with the help of a neurologist, Early On speech therapist, Occupational therapist, hospital rehab speech therapist, and U of M multidisciplinary evaluation clinicians, Chase finally received his diagnosis. We're got involved in an Autism Spectrum Disorder therapy group, home visits from a speech therapist and occupational therapist each week, private speech therapy twice a week, and a water therapy group to help with his sensory issues once a week. This is all combined with therapy that we provide at home. And remember, Chase is what they call "highly functioning" and we don't do as much as many other parents that we've met.

Chase is now doing much better, but it's still very hard. He now has at least as many words as his 13-month old sister and is gaining more words and sign language weekly. So much of our attention and energy goes to him, it's hard to feel like our life is anything close to normal. I was not able to work full time because of his various therapies. He couldn't handle daycare, so my mother thankfully watched him when I did come in to work. Many people we meet don't realize that anything's different about Chase. Some people think that I just am a bad mother and not able to control him and have told me as much. I'm able to handle that now, but there was a point that I didn't know how to respond and would end up breaking down in tears.

Originally, my health insurance through work covered our pediatrician prescribed speech therapy (at Sparrow

Pediatric Rehab). After the initial three months of pre-authorized coverage ran out, the office called PHP to confirm the next three months. At that point, we were denied coverage. When I called PHP, they said that a clerical error was the only reason we had been covered to begin with. The reasoning is that being a pervasive disorder, the insurance company does not feel that autism is treatable. I was so upset that I pretty much had the nurse who reviewed and denied the request in tears. I said, "So, you're telling me that the insurance company believes that my son is a lost cause and that treatment is useless?" It's insulting and ridiculous.

This therapy was a huge factor in Chase's progression with speaking. Before we started, he didn't say Momma or Daddy. Now he uses both. It is in our health plan wording that speech is just covered for stroke, head injury, and congenital anomalies. I would think that a neurological condition would fall into that somehow, but Physicians Health Plan **does not offer** any plans that do not **specifically exclude** all Autism Spectrum Disorders. So, even if my company wanted their insurance to cover ASDs, they could not purchase a policy that covers it.

Thankfully my son is in a preschool program for Autistic Spectrum Children and is still progressing, but I am certain that he would have progressed much faster if we had continued to receive those services. Also the financial and emotional burden has been significant. After working for 6 months on part-time unpaid FMLA, I had to start working full time again. We charged up credit cards as we ran out of money some months. We have little savings. The emotional stress of dealing with the disorder, the insurance companies, and still trying to work and keep our family together has been devastating at times. I've been diagnosed with depression and have been taking medication to reduce the effects.

I've contacted my local legislators urging them to support this kind of bill without getting much in response so far. I truly hope that we can come to a resolution that helps everyone out in the long run.

Thank you,
Sally Johnson
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